Two worlds: Adolescents' strategies for managing life with a parent in hospice

DENICE KOPCHAK SHEEHAN, PH.D., R.N.,[1] M. MURRAY MAYO, PH.D., R.N.,[2]
GRACE H. CHRIST, PH.D., D.S.W.,[3] KIM HEIM, M.S.N., R.N., F.N.P-B.C.,[4]
STEPHANIE PARISH, M.A.T., B.S.,[1] GHADA SHAHROUR, M.S.N., R.N.,[1] AND
CLAIRE BURKE DRAUCKER, PH.D., R.N., F.A.A.N.[5]

[1]Kent State University College of Nursing, Kent, Ohio
[2]Ursuline College, The Breen School of Nursing, Pepper Pike, Ohio
[3]Columbia University School of Social Work, New York, New York
[4]Department of Hematology/Oncology, Akron General Medical Center Physicians Partner Group, Akron, Ohio
[5]Indiana University School of Nursing, Indianapolis, Indiana

ABSTRACT

Objective: This study aimed to generate an explanatory model of the coping strategies that adolescents employ to manage the stressors they experience in the final months of their ill parent's life and shortly after their death.

Method: The sample included 26 families of adolescents with a parent receiving care in a large hospice program in northeastern Ohio. A semistructured interview was conducted with 14 ill parents, 17 well parents/guardians, and 30 of their adolescent children before the parent's death and, additionally, with 6 of these families after the death. The interviews were audiotaped, transcribed verbatim, and analyzed using a grounded-theory approach.

Results: The participants described two worlds that constituted the lives of the adolescents: the well world of normal adolescence and the ill world of having a parent near the end of life. The adolescents experienced a common challenge of living in two worlds and responded to the challenge with a process we labeled "managing two worlds." Five stages through which adolescents manage their worlds were identified: keeping the ill world and the well world separate; having the ill world intrude into the well world; moving between the ill world and the well world; being immersed in the ill world; and returning to the well world having been changed by the ill world.

Significance of results: The explanatory model of "managing two worlds" outlines a complex and nuanced process that changes over time. The model can be used by health professionals who seek to help adolescents navigate this critical time when their parents are dying or have recently died. These results can also be used to inform the development of interventions that assist families with strategies tailored to an adolescent's specific needs. Future research should investigate associations among the process of "managing two worlds" and outcomes related to adolescent bereavement.

KEYWORDS: Adolescents/youth, Hospice, Parental death, Advanced cancer, Qualitative research

INTRODUCTION

In 2012, almost 175,000 people between the ages of 34 and 64 years were estimated to have died while in hospice care (National Hospice and Palliative Care Organization [NHPCO], 2013), and many of these individuals had children. Although research has shown that parentally bereaved children may experience long-term effects, including greater rates of early mortality (Li et al., 2014), they are likely to show the greatest distress just prior to the parent's death (Saldinger et al., 2003; 2005). Parentally bereaved children can

Address correspondence and reprint requests to: Denice Kopchak Sheehan, Kent State University, College of Nursing, Henderson Hall, P.O Box 5190, Kent, Ohio 44242-0001. E-mail: dsheeha1@kent.edu

177

exhibit a host of negative effects, including sleep disturbances; emotional responses such as denial, anger, aggression, despair, guilt, anxiety, depression, and suicidal ideation; interpersonal problems such as withdrawal, loneliness, and social isolation; blaming self or others for the parent's illness; and behavioral problems such as sexual promiscuity and impaired school performance (Beale et al., 2004; Cait, 2005; Christ, 2000; Gazendam-Donofrio et al., 2010; Kennedy & Lloyd-Williams, 2009; Patterson & Rangganadhan, 2010; Vanheule & Hauser, 2008).

Adolescents whose parents are dying are a unique population. They experience the normal challenges of adolescent development including rapid physical changes, concerns about their appearance, developing their identity, establishing autonomy, seeking independence from parents, and focusing on peer and romantic relationships (Smetana, 2011; Levina & Ivanova, 2012). In addition, they experience the stressors of having a parent who is dying. They report, for example, that their homes are often transformed into "death's waiting room" (Buchwald et al., 2012) and that watching a parent die can be particularly traumatic (Saldinger et al., 2005). Other stressors include caretaking responsibilities (Phillips, 2014; Beale et al., 2004; Folkner & Davey, 2002), restrictions on time spent in school activities and socializing with friends (Phillips, 2014; Cait, 2005; Christ & Christ, 2006), witnessing the parent's symptoms and physical decline (Saldinger et al., 2005; Sheehan & Draucker, 2011), fear of abandonment and family dissolution (Christ, 2000), isolation from peers, and attempts to maintain normalcy by suppressing or minimizing feelings of distress (Davey et al., 2003; Huizinga et al., 2005; Bugge et al., 2008; Kennedy & Lloyd-Williams, 2009; Giesbers et al., 2010; Sheehan & Draucker, 2011). The stress of having a parent who is dying can be exacerbated by preexisting family dysfunction, including disturbed communication patterns and parenting practices (Sheehan et al., 2014), and the preexisting mental health and substance abuse problems of family members (Christ & Christ, 2006; Huizinga et al., 2003; Krattenmache et al. 2012; Riley & Fenton, 2007; Thastum et al., 2008; Timko et al., 2002; Zabora et al., 2001). Between 20 and 32% of adolescents experience clinically elevated levels of emotional and behavioral problems throughout the first year after a parent is diagnosed with a terminal illness (Visser et al., 2004).

After a parent's death, adolescents show greater levels of major depressive episodes and depressive symptoms (Cerel et al., 2006; Dowdney, 2000; Gray et al., 2011) and posttraumatic stress disorder (Melhem et al., 2008) than their nonbereaved peers. Depression in parentally bereaved adolescents can extend to two years following the death (Gray et al., 2011; Brent et al., 2009). Predictors of depression

in this population include: losing a mother, low self-esteem, blaming others, complicated grief, and negative coping (Brent et al., 2009). Poor family cohesion before and after the death of a parent is also associated with an increased risk for self-injury (Bylund Grenklo et al., 2014).

Some researchers have described children's coping strategies when a parent is near the end of life. One common strategy is the use of distraction or keeping busy, including participating in sports, socializing with friends, engaging in hobbies, watching television, and using computers (Phillips, 2014; Buchwald et al., 2012; Kennedy & Lloyd-Williams, 2009). Research on whether social and professional support aids in coping has been mixed. Some studies suggest that adolescents do not want to talk about their ill parents, do not seek support from their siblings, and do not believe that healthcare providers can help them (Dehlin & Reg, 2009), whereas other studies suggest these children do want to talk about their experiences and share information with friends, teachers, and classmates (Phillips, 2014; Bugge et al., 2008; Kennedy & Lloyd-Williams, 2009). No studies, however, have provided a robust description of coping strategies that change over time when a parent is dying, especially from the perspectives of the adolescents and their families.

Despite the negative, and at times long-lasting, effects of parental bereavement and the unique challenges of adolescents whose parents are dying, no empirically supported interventions have been developed to assist adolescents during this critical time period. To develop such interventions, more information is needed to better understand how adolescents cope when a parent has a life-limiting illness. The purpose of our study was to generate an explanatory model of coping strategies that adolescents use to manage the stressors that occur during the final months of an ill parent's life and shortly after his or her death. Grounded-theory methods (Charmaz, 2006; Glaser & Straus, 1967; Glaser, 1978) were employed to generate an explanatory model.

METHODS

Families of adolescents with a parent in hospice were recruited from a large hospice program in northeast Ohio. Approvals were obtained from the institutional review board at the investigators' university and from the hospice facility. Adults in the hospice program were eligible to participate if they were able to speak, write, and understand English; had the cognitive ability and physical stamina to complete an interview; and had children between the ages of 12 and 18.

The research associate met regularly with the hospice staff to describe the study, answer questions, and

elicit help in identifying families who met study criteria. The contact information for these families was given to the research associate, who screened them to determine eligibility. For families who were eligible and interested in participating in the study, individual interviews with the ill parents, well parents, and adolescents were scheduled.

After the parents consented for themselves and their adolescents and assent was obtained from the adolescents, individual interviews were conducted between December of 2010 and July of 2012 in the participants' homes or in a private room at the hospice facility. The interviews included open-ended questions in which all family members were separately asked to describe the adolescents' experiences from the time their ill parents were diagnosed until they were near death or had died, including how the adolescents managed the stressors of having a parent with a life-limiting illness or of losing a parent. A $35.00-honorarium was given to each participant immediately after signing the consent form.

Interviews and fieldnotes were digitally recorded and transcribed verbatim. The interviewer reviewed each transcript for accuracy. Data were managed with the aid of the NVivo9 computer software program (QSR International, 2010).

Some 26 of the 45 families who met the inclusion criteria agreed to participate in the study; those who declined usually did not give a reason. Although the ill parents in 11 families were too ill to complete an interview, the well parents and/or adolescents participated. Five families had two adolescents who participated. Parent surrogates, including grandparents or significant others acting in a parenting role, were included in the study. Six families that included six well parents and nine adolescents participated in an additional interview after the ill parent's death. Enrollment data are depicted in Figure 1. Participant characteristics are presented in Table 1.

Analysis

The research team included three doctorally prepared nurse researchers, one doctorally prepared social work researcher, and one graduate nursing student. The team analyzed data from interview narratives and fieldnotes using grounded-theory methods. Three levels of coding were conducted to transform the data into an explanatory model (Charmaz, 2006; Glaser & Straus, 1967; Glaser, 1978). During first-level coding, any phrases, sentences, or paragraphs revealing information related to the coping strategies of adolescents were labeled with code words that captured the essence of participants' remarks. The participants' words were used as labels when possible. A list of codes was developed, and various display grids were used to organize codes attributable to the three participant groups
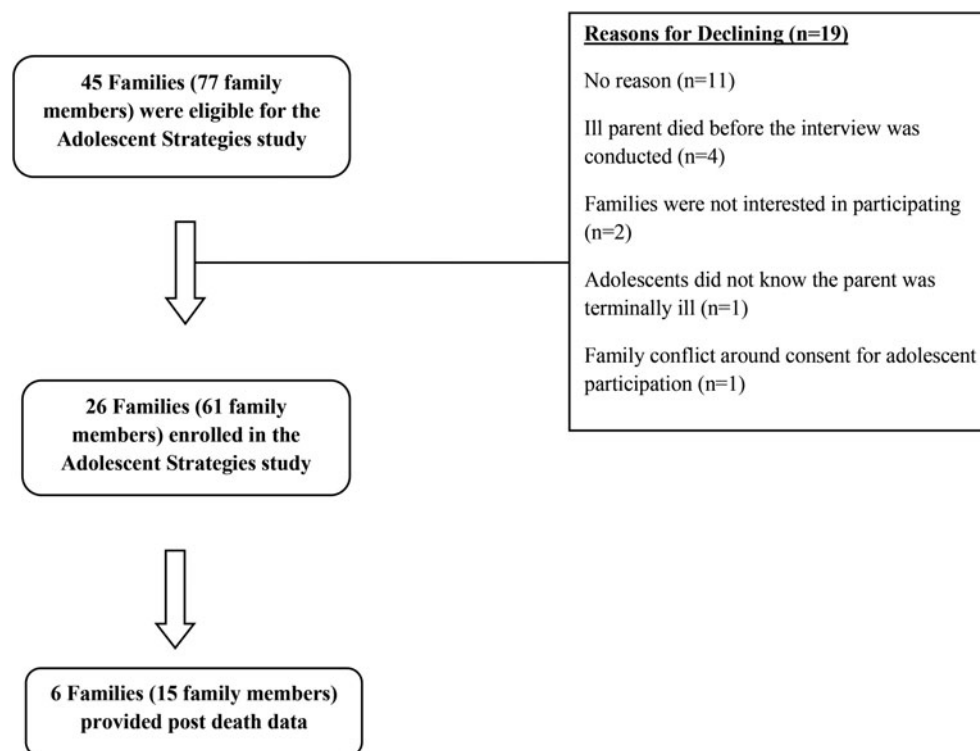

Reasons for Declining (n=19)

No reason (n=11)

Ill parent died before the interview was conducted (n=4)

Families were not interested in participating (n=2)

Adolescents did not know the parent was terminally ill (n=1)

Family conflict around consent for adolescent participation (n=1)

45 Families (77 family members) were eligible for the Adolescent Strategies study

26 Families (61 family members) enrolled in the Adolescent Strategies study

6 Families (15 family members) provided post death data

Fig. 1. Study participants.

Table 1. *Participant characteristics*

	Adolescents (n = 30)	Ill Parent (n = 11)	Well Parent (n = 20)
Gender			
Male	12 (40%)	6 (60%)	4 (20%)
Female	18 (60%)	5 (40%)	16 (80%)
Age (years)			
Mean	15	55	50
Range	12–18	40–62	34–60
Religious affiliation			
Catholic	9 (30%)		
Protestant	6 (20%)		
Jehovah's Witness	1 (3%)		
None	4 (14%)		
No response	10 (33%)		
Race			
Caucasian	22 (73%)		
African American	5 (17%)		
Mixed race	2 (7%)		
No response	1 (3%)		
Current family annual income (n = 26)			
Under $10,000	5 (19%)		
$10,001–30,000	5 (19%)		
$30,001–50,000	4 (16%)		
Over $50,001	7 (27%)		
No response	5 (19%)		
Diagnosis (n = 26)			
Cancer		21 (81%)	
ALS		1 (5%)	
MS		1 (5%)	
Pulmonary disease		1 (5%)	
Mad cow		1 (5%)	
No response		1 (5%)	
Time from interview to parent's death (days)			
Mean	41		
Range	0–183		

Note. The ill parent in four families died within one week of the interview. One parent died during the adolescent's interview.
ALS = amyotrophic lateral sclerosis; MS = multiple sclerosis.

(i.e., adolescents, ill parents, and well parents). For second-level coding, the codes were compared and then collapsed into categories. The researchers employed an iterative analytic process that involved moving from specific incidents in the data to evolving categories and then checking the categories against additional incidents. The researchers returned to the data to saturate, refine, and define the categories as they emerged. In third-level coding, the relationships among the categories were examined. A process of constant-comparison analysis and reflection on the data, selective sampling of the literature, and selective sampling of participants was utilized to generate an explanatory model that was substantively dense.

Several procedures were used to enhance the trustworthiness of our findings. The perspectives of the three groups (i.e., adolescents, ill parents, and well parents) were used to construct the model. The analysis was conducted by an interdisciplinary research team that included nursing and social work professionals. Peer debriefing and discussion of emerging findings occurred at weekly team meetings. All methodological and analytic decisions were documented in an audit trail. The sample is described with detailed information related to demographic characteristics, health status, and family structure, thereby enabling readers to determine whether the findings were relevant to a particular group.

The Explanatory Framework: Managing Two Worlds

Participants described two worlds that constituted the lives of the adolescents while their parents were seriously ill and shortly after their death: the well world and the ill world. The worlds were spheres in which the adolescents carried out practical daily activities and thus had no physical boundaries. The well world was the sphere in which the adolescents lived their "normal" lives. In this world, they attended school, spent time with peers, and engaged in social activities. The ill world was the sphere in which they dealt with the life-limiting illness and death of their parents. In this world, they spent time with their ill parents, visited them in the hospital or hospice facility, provided care for them in the home, and took on additional family responsibilities such as household tasks and caring for siblings.

A common problem faced by adolescents was the challenge of living in both worlds. One 17-year-old son stated,

> When I wake up, it is a school day, but when I get back from school, it is basically like a workday because I am staying home, I am watching over the house, and I am taking care of everything there. It is kind of like I am a teenager and a grown-up. I go to school as a teenager. I get back, and I am not a teenager anymore. I am a grown-up, you know, and that alone, it could overload anybody's head just thinking about it all.

The adolescents responded to the problem of living in two worlds with a process the team labeled "managing two worlds." The term "managing" was chosen rather than "coping" because dealing with the complexities of living in two worlds involved more than coping with the stressors of the parents' illness; indeed, it entailed more broadly running one's life in

the context of multiple demands. The process of managing two worlds evolved in common ways across the duration of the parents' illnesses and included five stages: keeping the ill world and the well world separate, having the ill world intrude into the well world, moving between the ill world and the well world, being immersed in the ill world, and returning to the well world having been changed by the ill world. The stages, characteristics common to each stage, and representative quotes are presented in Table 2.

Keeping the Ill World and the Well World Separate

The participants described an initial stage in which the adolescents tried to keep their two worlds apart. This stage usually began when the ill parents were diagnosed with a life-limiting illness. The stage could be brief if the parent was diagnosed close to death, such as with advanced cancer, or lengthy if the parent had an illness with a more chronic trajectory, such as amyotrophic lateral sclerosis. During this stage, adolescents wanted life to be "normal" and did not want to be seen as different from their peers.

One strategy adolescents used to keep the two worlds separate was staying busy with well-world activities to keep themselves from worrying about their parents' declining health. For example, one 17-year-old daughter explained, "Being at school is a distraction because it gives me other things to do instead of worry about home, what is making me sad. At school it is like school mode; [at home it is] home mode." Another 14-year-old daughter stated, "I busy myself until I just kind of forget, and it seems to work for me. But I mean then when I come home it's like, 'Oh yeah, my dad's sick, right.' And I guess I get upset." Other well-world activities that distracted the adolescents from the ill world included going to school, going out with friends, participating in sports, listening to music, writing, playing video games, and sleeping.

Another strategy adolescents used to keep the two worlds apart was maintaining their privacy. The adolescents kept the ill world out of their well world by not revealing or discussing their parent's illness or by keeping their friends away from their ill parents. One 14-year-old adolescent daughter explained, "They [friends] were supportive, and they wanted to see him, but like I didn't want to put him out there like that, like come see how scratched up and hurt he is, so I didn't have them, let them see him or come in."

Parents often helped adolescents keep the worlds separate by encouraging them to keep up with their "normal" activities and limiting their ill-world burdens. One 46-year-old well father commented, "I feel sometimes I should have them do more, but they need to be kids through this, and at the same time they are helping me with her [the ill mother] in little ways that are big to me." Adolescents who lacked a close relationship with the ill parent found it easier to separate the two worlds. A 13-year-old daughter of divorced parents explained, "My father (...) we weren't very close, and I feel like that makes it easier for me."

Having the Ill World Intrude into the Well World

The participants described a second stage in which the ill world intruded into the well world. This intrusion occurred as the ill parents' health declined and the adolescents observed their parents getting weaker, changing in appearance, receiving more intense medical treatment, and becoming less able to accomplish daily tasks. The ill world intruded upon the well world when the adolescents found themselves thinking and being concerned about their ill parents even when the adolescents were engaged in well-world activities. One 12-year-old daughter stated, "Most of the time I focus on school, but like I see myself drifting off sometimes and just thinking back to the old times when he was able to do things— It is just hard." Adolescents were especially likely to worry about their ill parents after a difficult incident, such as when they were brought to the hospice facility or "something happening at home." The adolescents were distressed by these thoughts because they could not keep them at bay, and several cried or "sobbed" when they occurred. One 14-year-old daughter stated, "I started crying on the bus because I wanted to go home, and I don't know, it is hard. I feel like I should be home with her, and instead I have to go to a stupid football game." During this stage, some adolescents began to accept support from concerned family and friends. One 16-year-old daughter, for example, revealed, "I was in the middle of class, and I started crying, and, honestly she [a friend] just stood up and gave me a hug, and it really did, it made everything better."

Moving Between the Well World and the Ill World

The participants described a third stage in which the adolescents moved between the well world and the ill world. In this stage, they remained engaged in the well world but frequently moved into the ill world. The adolescents thus had a sense they were "doing it all."

Moving between the two worlds involved a sense of being vigilant as to when one needed to move from one world to another. As one 16-year-old son explained,

> Nowadays we seem more like firemen when firemen are at the firehouse. They are just kind of

Table 2. *Processes adolescents use to manage two worlds when a parent is dying*

Stages	Characteristics	Exemplar Quotes
KEEPING THE ILL WORLD AND WELL WORLD SEPARATE	Staying busy	
	Going to school	School was just like my escape …
	Going out with friends	I am always running around with my friends; that helps a lot too.
	Playing sports	And that's how I feel about sports. I play softball, gymnastics, and cheerleading.
	Listening to music	[Music] gives me that comfort and makes you like in your own world, and when you listen to that it is like, oh, everything is alright.
	Writing	I'll write a poem or a song or a story, and then I'll have gotten my feelings out but it doesn't like have to bring anyone else down."
	Playing video games	Usually I try and play video games— I always play basketball to get my mind off of things. That's usually my main distraction
	Watching television	When I start watching something that is funny, I don't think about anything else but that television show.
	Sleeping	When I see something going the wrong way, I step back, and like I am going to go to my room and sleep.
	Maintaining privacy	I don't want to deal with hearing about my mom and people go, "How is your mom doing?" (…) Then I just tell them I don't want to talk about it because I feel like I shouldn't be telling them news that we are not for sure about until she is actually gone and we can still hope for the better.
HAVING THE ILL WORLD INTRUDE INTO THE WELL WORLD	Thinking and worrying about the ill parent	When I get into to school— that is when I start thinking about stuff at home. Sometimes I get distracted like if something happens at home, and then when I go to school I just can't think and I can't do things. Sometimes and it sucks.
MOVING BETWEEN THE ILL WORLD AND THE WELL WORLD	Doing it all	I got normal teenager stuff, and then I have to deal with what is going on with my father— It is like I am leading a double life right now— I go to school as a teenager. I get back, and I am a grown-up, and that alone, it could overload anybody's head just thinking about it all.
		She is sick, she just lays down, and I just do my own thing, go kick it with friends and everything, go and call her and check up on her, when she calls and needs something, I am there
	Striking a balance of support and privacy	Being completely honest with the people you trust most— So they can be there for you— definitely my friends.
		I don't tell everybody about my situation because I don't want my business to be out everywhere— I talk to my best friend about it and my boyfriend because they listen to me— My best friend knows what I am going through because her mother is very sick— So she knows.
BEING IMMERSED IN THE ILL WORLD	Taking on caretaking responsibilities	I am the person he [ill father] always calls— I would like have to get him water and cook him food, help clean him up, help his pajamas on, all that stuff [parents do not get along]
		The fun part is learning how to help somebody when they are not feeling well— The hard part is like, getting them their food, and like giving their buckets
	Spending time with the parent	Instead of blowing off things and going to hang out with your friends, actually be happy and stay home with your mom and cuddle with her and hold her hand— Because I know she is going to be gone soon, and this is all the time I have left [crying].

RETURNING TO THE WELL WORLD HAVING BEEN CHANGED BY THE ILL WORLD		
	Feeling the presence of the deceased parent	I still hear my dad's voice in my head. I still know what he would want me to do— When I think about whether or not I should or should not do something, his voice definitely pops into my head and helps me think it through.
	Connecting with peers who lost a parent	It is weird, but it is good to know like that other people are going through the same thing that you are, and you can connect with them on a different level than like say somebody who hasn't had that happen. Many of us have like a grandparent [die], but it is different when it is your parent—The people who have also lost parents at our school are just really comforting even if you are not close with them.
	Moving on	I don't think she [her deceased mother] would've liked me thinking about it [her death] all the time. I think she would want me just to move on because, if I think about her. All it does is really hold me back. It is nice to think about her every now and then, but it is not really worth getting all worked up over things."

hanging out and doing stuff and playing cards or something, but then when the fire bell rings, we all just have to jump down the pole and be in a more ready mode than we had to be in before he was sick, so there's definitely been some changes as far as how quickly we can assemble and be ready for anything— Keep that ear open and the boots next to the door— I am not hampered as much by my dad's sickness as I am just concerned that I always show up to help him.

Another aspect of moving between the two worlds involved striking a balance between having others in the well world aware of the parents' illness and maintaining privacy. Though the adolescents did not want others' knowledge of their parents' illness to be the focus of their well world, they recognized the need for others to be aware of their situation. Some, for example, were grateful when the school officials or their parents informed their teachers about the parent's advancing illness so the teachers could help them move between the two worlds. One 16-year-old daughter stated, "My guidance counselor at school and my teachers know what is going on. The guidance counselor is supposed to tell the teachers just to make sure they know what's going on, and that if I am lacking in one of my classes they can help me out more."

Being Immersed in the Ill World

The participants described a fourth stage in which the adolescents begin to withdraw from the well world and become more absorbed by the ill world. As the health of their ill parents declined further and they grew closer to death, the adolescents focused more on their ill parents and their families and gave up many of their well-world activities. They became immersed in the ill world by taking on caregiving responsibilities and spending more time with the ill parent.

The caregiving responsibilities that the adolescents took on were in many cases considerable. Some did extensive household tasks, provided personal care for the ill parents, and cared for siblings. Though some adolescents appreciated the opportunity to care for their dying parents and to "help out" their families, the caregiving responsibilities could occupy much of the adolescents' time and could feel burdensome. The responsibilities of having a parent near death were especially taxing for adolescents in single-parent families and those in which the well parents worked outside the home. One 14-year-old daughter stated, "I am stressed out, and I have to do things that, not normal people, but just teenagers don't have to do sometimes—making dinner every

night after cheerleading, coming home and not being able to go out on Friday nights, or staying home with my mom, or having to go to the hospital." One 17-year-old son said, "I am going to start looking for one [a job] just in case he does pass away, because then I will have to be the man of the house."

The adolescents also became more immersed in the ill world as they simply spent more time with their families. The adolescents would often choose to stay home just to "hang out" with their ill parents as the adolescents realized there was little time left. During these times, the adolescents would offer emotional support and express affection toward the ill parent. One 14-year-old daughter explained, "Instead of blowing off things and going to hang out with your friends, actually be happy and stay home with your mom and cuddle with her and hold her hand— because I know she is going to be gone soon, and this is all the time I have left [crying]." For some adolescents, being immersed in the ill world meant keeping vigil with their ill parents as death approached.

Returning to the Well World Having Been Changed by the Ill World

The final stage occurred after the ill parents' deaths and funerals, when the adolescents fully resumed their well-world activities. Several participants emphasized, however, that the adolescents were fundamentally changed by the loss of their parents, and their well world was no longer the same.

The well world of the adolescents was different, because most others in the well world knew about their parents' death and therefore freely offered support and condolences. Feelings connected to others in the well world were now a comfort for most of the adolescents. One 17-year-old son discussed responses he received on Facebook about the loss of his father:

> I really enjoyed reading everything that everyone had to say. It was just kind of nice to see how many people said they were there for me, whether they would be there or not, but it was just kind of nice to see everything everybody had to say.

Another way in which the well world was changed for the adolescents was that they continued to feel the presence of their lost parents, and thus many well-world activities were dampened by their sense of loss. One 13-year-old son said about leaving for school, "He's not there to hug me bye— When I call home sick I can't talk to him. [Sniffling] When I come home from school, it's like he's not there." Another 15-year-old daughter stated, "[I feel] sudden temporary urges of grief. I will just be sitting around

doing nothing, and I will eat a granola bar, and I will start to cry and be like 'oh daddy.' "

The well world had changed for a few of the adolescents, who now felt that they had a special kinship with other adolescents who had lost a parent. One 18-year-old son stated,

> Throughout the year I have had particular points where you have the realization, sudden hits of grief, moments of grief, they can't be predicted— He [friend at college] had gone back home because his dad had Lou Gehrig's, and so for a couple of days he was gone, I think a week or two, and then he came back and his dad died— It reminded me of my dad, and then we got that moment of grief, but also that moment of not being alone.

The well world thus offered to the adolescents a chance to bond with peers who had had similar experiences of loss.

Some adolescents believed that they had matured because of the death of their parents, and several indicated they now felt it was time to "move on." One 18-year-old son said,

> I think that I would've been less motivated, less determined had my father not gotten sick and died. That is where I think it all came together as the start of my personal growth, because there wasn't that sort of protective shadow anymore. As soon as my dad stopped being the one who could take care of everything, that for me was taking on more responsibility, and the more responsibility you have, the faster you grow up.

Although the adolescents continued to mourn the loss of their parents, several expressed a readiness to return fully to the well world, having grown through their loss. These adolescents had a sense that this is what their deceased parents would have wished for them.

DISCUSSION

These results substantiate the findings of prior research indicating that adolescents cope with the life-limiting illness of a parent by integrating the illness experience into their everyday lives (Phillips, 2014; Finch & Gibson, 2009), using the distraction of normal activities to avoid worry (Phillips, 2014; Thastum et al, 2008), and maintaining normality as long as possible (Kennedy & Lloyd-Williams, 2009). Other researchers have also reported that adolescents often provide care for the ill parent and younger siblings and take on household responsibilities, which often limits the time they spend with their

friends (Phillips, 2014; Cait, 2005; Christ & Christ, 2006; Thastum et al, 2008; Kennedy & Lloyd-Williams, 2009; Sheehan & Draucker, 2011). Our findings also resonated with studies finding that adolescents often preferred not to talk about their parent's illness, at least initially (Huizinga et al., 2005; Thastum et al, 2008; Dehlin & Reg, 2009; Kennedy & Lloyd-Williams, 2009; Giesbers et al., 2010), but later could find comfort in talking with their siblings and friends, especially when they shared common experiences (Phillips, 2014; Bugge et al., 2008; Finch & Gibson, 2009). Our findings add to the literature, however, by providing a model that highlights the challenges of living "normally" in the well world while also dealing with parental illness in the ill world and that outlines the ways in which this occurs over time. The model thus captures the dynamic process by which adolescents continuously adapt in the face of a parent's declining health and impending death, as well as their own bereavement.

Our findings should be considered in the context of several limitations. Our sample was drawn from a single hospice facility, and it is likely that families who do not use hospice services may have different experiences surrounding parental bereavement. Given that the interviews occurred near the end of life or soon after the death of a parent, it might have been difficult for participants to discuss negative feelings or to reveal conflictual family dynamics. This limitation was offset to some degree by having multiple family members describe the same incidents. Also, our sample size did not allow us to explore how variation in family characteristics (e.g., religious affiliation, race, family income) may have influenced the adolescents' experiences. A prospective study with a larger sample and robust representation from different demographic groups would permit such an exploration.

The findings have implications for healthcare professionals who work with bereaved adolescents. We concur with Bylund Grenklo and colleagues' (2013) recommendation that interventions need to be developed that target adolescents or their families before and after the parent's death to ameliorate short- and long-term negative outcomes. Healthcare professionals can use the model developed for this study as a springboard to initiate conversations about how adolescents are managing their two worlds, to explore which stage they are in, and to help them decide how they wish to manage the tensions they experience in managing the demands of each world. The model indicates that the role of healthcare professionals or other adults who seek to help bereaved adolescents may change over time; adolescents may reject adult help when they are trying to keep the ill world out of their well world but welcome it when the ill world intrudes.

Future research should expand the model by increasing the sample size and including families with more ethnic, religious, and regional diversity to explore population variations of "managing two worlds." Researchers should also explore how variations in this process are related to adolescent outcomes. A longitudinal study that follows families from diagnosis to several years post death and that includes multiple data sources such as observation and journaling would provide a more robust understanding of how adolescents cope over time. Parentally bereaved adolescents are an understudied and at-risk group, and more information is needed to develop targeted interventions to improve the quality of their lives during and following this significant life trauma—the loss of a parent.

ACKNOWLEDGMENTS

REFERENCES

Beale, E.A., Sivesind, D. & Bruera, D. (2004). Parents dying of cancer and their children. *Palliative & Supportive Care*, 2(4), 387–393.

Brent, D., Melhem, N., Donohoe, M.B., et al. (2009). The incidence and course of depression in bereaved youth 21 months after the loss of a parent to suicide, accident, or sudden natural death. *The American Journal of Psychiatry*, 166(7), 786–794.

Buchwald, D., Delmar, C. & Schantz-Laursen, B. (2012). How children handle life when their mother or father is seriously ill and dying. *Scandinavian Journal of Caring Sciences*, 26(2), 228–235.

Bugge, K.E., Helseth, S. & Darbyshire, P. (2008). Children's experiences of participation in a family support program when their parent has incurable cancer. *Cancer Nursing*, 31(6), 426–434.

Bylund Grenklo, T., Kreicbergs, U., Hauksdóttir, A., et al. (2013). Self-injury in teenagers who lost a parent to cancer: A nationwide, population-based, long-term follow-up. *JAMA Pediatrics*, 167(2), 133–140.

Bylund Grenklo, T., Kreicbergs, U., Valdimarsdóttir, U.A., et al. (2014). Self-injury in youths who lost a parent to cancer: Nationwide study of the impact of family-related and health care–related factors. *Psycho-Oncology*, 23(9), 989–997

Cait, C.A. (2005). Parental death, shifting family dynamics, and female identity development. *Omega*, 51(2), 87–105.

Cerel, J., Fristad, M.A., Verducci, J., et al. (2006). Childhood bereavement: Psychopathology in the two years postparental death. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(6), 681–690.

Charmaz, K.C. (2006). *Constructing grounded theory.* Thousand Oaks, CA: Sage.

Christ, G. (2000). Impact of development on children's mourning. *Cancer Practice*, *8*, 72–81.

Christ, G.H. & Christ, A.E. (2006). Current approaches to helping children cope with a parent's terminal illness. *CA: A Cancer Journal for Clinicians*, *56*(4), 197–212.

Davey, M., Askew, J. & Godette, K. (2003). Parent and adolescent responses to non-terminal parental cancer: A retrospective, multiple-case pilot study. *Families, Systems, & Health*, *21*, 245–258

Dehlin, L. & Reg, L.M. (2009). Adolescents' experiences of a parent's serious illness and death. *Palliative & Supportive Care*, *7*(1), 13–25.

Dowdney, L. (2000). Annotation: Childhood bereavement following parental death. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *41*(7), 819–830.

Finch, A. & Gibson, F. (2009). How do young people find out about their parent's cancer diagnosis: A phenomenological study? *European Journal of Oncology Nursing*, *13*, 213–222.

Folkner, R.A. & Davey, M. (2002). Children and adolescents of cancer patients: The impact of cancer on the family. *The American Journal of Family Therapy*, *30*, 63–72.

Gazendam-Donofrio, S.M., Hoekstra, H.J., Winette, T.A., et al. (2010). Adolescents' emotional reactions to parental cancer: Effect on emotional and behavioral problems. *Journal of Pediatric Psychology, 36*(3), 346–359.

Giesbers, J., Verdonck-de Leeuw, I.M., van Zuuren, F.J., et al. (2010). Coping with parental cancer: Web-based peer support in children. *Psycho-Oncology*, *19*, 887–892.

Glaser, B.G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: Sociology Press.

Glaser, B.G. & Straus, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine.

Gray, L.B., Weller, R.A., Fristand, M., et al. (2011). Depression in children and adolescents two months after the death. *Journal of Affective Disorders*, *135*, 277–283.

Huizinga, G.A., van der Graaf, W.T., Visser, A., et al. (2003). Psychosocial consequences for children of a parent with cancer. *Cancer Nursing*, *26*, 195–202.

Huizinga, G.A., Visser, A., van der Graaf, W.T., et al. (2005). The quality of communication between parents and adolescent children in the case of parental cancer. *Annals of Oncology*, *16*, 1956–1961.

Kennedy, V.L. & Lloyd-Williams, M. (2009). How children cope when a parent has advanced cancer. *Psycho-Oncology*, *18*, 886–892.

Krattenmacher, T., Kuhne, F., Ernst, J., et al. (2012). Parental cancer: Factors associated with children's psychosocial adjustment. A systematic review. *Journal of Psychosomatic Research*, *72*, 344–356.

Ļevina, J. & Ivanova, N. (2012). The self-concept of adolescents with different social status in peer cliques. *Baltic Journal of Psychology*, *13* (1, 2), 98–112.

Li, J., Vestergaard, M., Cnattingius, S., et al. (2014). Mortality after parental death in childhood: A nationwide cohort study from three Nordic countries. *PLoS Medicine*, *11*(7), e1001679. Available from http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001679.

Melhem, N.M., Walker, M., Mortiz, G., et al. (2008). Antecedents and sequelae of sudden parental death in offspring and surviving caregivers. *Archives of Pediatrics & Adolescent Medicine*, *162*(5), 403–410.

National Hospice and Palliative Care Organization (NHPCO) (2013). *NHPCO's facts and figures: Hospice care in America.* Available from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf.

Patterson, P & Rangganadhan, A. (2010). Losing a parent to cancer: A preliminary investigation into the needs of adolescents and young adults. *Palliative & Supportive Care*, *8*(3), 255–265.

Phillips, F. (2014). The experience of adolescents who have a parent with advanced cancer: A phenomenological inquiry. *Palliative & Supportive Care*. doi: http://dx.doi.org/10.1017/S1478951514001023. Epub ahead of print September 3, 2014.

QSR International (2010). *NVivo qualitative data analysis program.* Melbourne: QSR International.

Riley, J. & Fenton, G. (2007). A terminal diagnosis: The carers' perspective. *Counselling and Psychotherapy Research*, *7*(2), 86–91.

Saldinger, A., Cain, A. & Porterfield, K. (2003). Managing traumatic stress in children anticipating parental death. *Psychiatry*, *66*(2), 168–181.

Saldinger, A., Cain, A. & Porterfield, K. (2005). Traumatic stress in children anticipating parental death. *The Prevention Researcher*, *12*(4), 17–20.

Sheehan, D.K. & Draucker, C.B. (2011). Interaction patterns between parents with advanced cancer and their adolescent children. *Psycho-Oncology*, *20*(10), 1108–1115.

Sheehan, D.K., Draucker, C.B., Christ, G.H., et al. (2014).Telling adolescents a parent is dying. *Journal of Palliative Medicine*, *17*(5), 512–520.

Smetana, J.G. (2011). *Adolescents, families, and social development: How teens construct their worlds.* West Sussex: Wiley–Blackwell.

Thastum, M., Johansen, M.B., Gubba, L., et al. (2008). Coping, social relations, and communication: A qualitative exploratory study of children of parents with cancer. *Clinical Child Psychology and Psychiatry*, *13*(1), 123–138.

Timko, C., Cronkite, R.C., Berg, E.A., et al. (2002). Children of parents with unipolar depression: A comparison of stably remitted, partially remitted, and non-remitted parents and non-depressed controls. *Child Psychiatry & Human Development*, *32*, 165–185.

Vanheule, S. & Hauser, S. (2008). A narrative analysis of helplessness in depression. *Journal of the American Psychoanalytic Association*, *56*, 1309–1330.

Visser, A., Huizinga, G.A., van der Graff, W.T., et al. (2004). The impact of parental cancer on children and the family: A review of the literature. *Cancer Treatment Reviews*, *30*(8), 683–694.

Zabora, J., Brintzenhofeszoc, K., Curbow, B., et al. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, *10*, 19–28.